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What it means to be a palliative care volunteer in eight European countries

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Title: What it means to be a palliative care volunteer in eight European countries: a qualitative analysis of accounts of volunteering

Abstract: This paper addresses the stories of volunteers in hospice and palliative care (HPC) from eight European countries. The aims of the paper are to explore the experiences of volunteers in HPC from their insider perspective, to understand why volunteers choose to work in this field and to understand what it means to them to be involved in palliative care in this way. Stories were collected by the European Association for Palliative Care (EAPC) Task Force for Volunteering contacts in each of the eight countries. The majority of stories (n=32) came from volunteers involved in different settings including adult patient's homes, hospices, hospitals and care homes. Twenty volunteers were female, six were male and ten did not give their gender. Stories were translated into English and a qualitative framework analysis was performed.

Volunteers were asked two questions: "What do you do as a volunteer?" "What does volunteering mean to you?" Three themes were identified from the data 1) What volunteers do 2) How volunteers approach their work and 3) What working in HPC means to volunteers.

The analysis revealed that common approaches to addressing and describing HPC volunteering in terms of tasks and roles could be expanded. To volunteers it is not about tasks, but about a part of their life, the impact upon which can be significant. The results of this paper, therefore, add to the understanding of volunteers, in the sense of giving attention, being with, and of compassion as a community resource to patients and families in difficult situations. Theories about presence and presencing might have value in further underpinning this contribution to palliative care. Understanding the extent and depth of the volunteers' experience will help to prevent the undervaluing of their contribution and increase the impact of their involvement.

Key words: Volunteer, volunteering, hospice and palliative care, narratives, stories, activities, meaning.

Background

Volunteers play a significant and distinctive role in supporting hospice and palliative care services in many countries (1-4,5). Research suggests that volunteers played a key role in instigating the modern hospice movement and continue to provide a range of support including direct practical, emotional and social support to patients and families, helping the wider organisation with fundraising. Several studies (6-8) propose that volunteers are recognised as a third resource, alongside professional and family carers, having a specific role alongside professionals and family care givers within the HPC team.

Much palliative care research on volunteering has focused on activity and motivations, with fewer studies exploring experiences, meaning and impact. Vanderstichelen et al. (9) suggest that considering HPC volunteering solely from the perspective of activities is to overlook the complexity of the role that volunteers play. Studies of HPC volunteers' experience (10,11,12) indicate that they derive

much meaning from their involvement. Volunteers find their work enriching and rewarding, and the reciprocal nature of volunteering is clear as they describe gaining as much as they give (10,11,13). Studies (10,12,13,14) also describe personal growth from volunteering, learning from experience and from patients. Volunteering in HPC often makes a significant impact on the volunteer's life with the death of patients they have supported leaving a lasting impression (10,15).

However, HPC volunteering is not without challenges (10,11,13). Volunteers do not always feel equipped or prepared effectively for their work resulting in lack of confidence (11,16). They sometimes have difficulty in reconciling their values with those of others, (11) and find witnessing, suffering and death difficult, especially that of young people (10).

Volunteers develop a deeper understanding of life and death (12,15) changing their perspectives and valuing their own lives more (10,13,14). For some, this meant considering their own mortality and becoming more accepting of death (14,16).

In order to involve and support HPC volunteers effectively, it is important to understand the meaning and impact of volunteering on their lives. This project aimed to elicit volunteers' personal stories of their involvement in HPC in their own words in order to examine their experiences more clearly.

Aims: The aims of the paper are to explore the experiences of volunteers in HPC from their insider perspective, to understand why they choose to work in this field and to understand what it means to them to be involved in this work.

Method:

The study design was a qualitative narrative analysis of the written accounts of volunteers.

Sample (or Participants)

Holloway and Freshwater (17) suggest that narrative research can often involve small numbers of participants as depth rather than breadth of data is important. We, therefore, aimed to recruit 40 volunteers, five from each of eight countries: Austria, Finland, France, Germany, Italy, Netherlands, Poland, and UK, countries that were active participants in the European Association for Palliative Care (EAPC) Task Force on Volunteering. Participants for the study were sought through the EAPC Task Force on Volunteering in HPC networks. Contacts in eight countries were asked to recruit five volunteers from each country, willing to write in their own language about their experiences of volunteering. The majority of the authors were not involved in the selection of volunteers and had no contact with them, although one author identified five potential participants in one country. There were no study inclusion or exclusion guidelines given, and no specific volunteering activities requested.

Data collection

The story structure was kept as open as possible to minimise any influence on the volunteers. A short information sheet was developed for country contacts and prospective participants. In order to give consistency to the stories, volunteers were asked to write a 400-500 words story around two key questions: "What do you do as a volunteer?" "What does volunteering mean to you?" The information sheet advised that the stories would be translated into English. The stories were translated from the native language, into English by speakers fluent in both English and the country language. Demographic data was not requested in order to protect the identity of volunteers who provided significant personal and sensitive information, especially from countries where volunteering is not so common. Original names were also replaced to protect anonymity.

Analysis

Authors 1,2,3 and 4 read the material carefully several times to become familiar with the information within every story and country. Since the stories showed a characteristic type of language use, the application of a discourse analysis was considered (18). However, due to the necessary translation from the native languages into English, this was considered less appropriate as the specific meaning from the chosen wordings could be lost in the translation.

A framework analysis (19) was applied as it fitted the material, the research questions and is helpful when members of the research team come from different disciplines and countries. Apart from one meeting in person, all team discussions were organized virtually, via the internet.

Themes derived from the data from 36 stories, were coded independently by authors 1,2 and 3. Coding was then compared and discussed by the researchers until agreement of the themes was reached. Based on these discussions, an analytical framework relating to the research questions was developed; a matrix with the respondents in rows and questions in columns. This provided a structure for systematically reducing the data and analysing the emerging themes. This enabled comparisons of themes in relation to the questions within and across stories.

Data were reduced where possible along with text fragments that referred to the meaning and 'couleur locale' of the volunteers' descriptions. Characteristic citations were marked. Interpretation of the data took place by finding similarities and differences between the themes identified with respect to the questions posed. Interpretations were checked by two authors (authors 1 and 2) and reviewed by authors 3 and 4. Quotes have been selected to illustrate the main themes identified, each labelled with a country participant number.

To improve the quality and rigour, analysis was undertaken by researchers from different disciplines and countries. Authors 1 and 2 analysed the data which was subsequently checked by authors 3 and 4. In addition, data was checked at each stage of the analysis until consensus among the researchers was achieved, thus reducing bias.

Results

Context and activities

Thirty-six stories were collected from eight countries. Four countries submitted four stories rather than the five requested France, Germany, Poland and UK. We do not know how many volunteers who were asked declined to participate. Twenty volunteers were female, six were male and ten did not give their gender.

The majority of volunteers (n=32) were involved in different adult HPC settings including patient's homes, hospices, hospitals and care homes. Two volunteered in children's palliative care and two in hospice bereavement services. Two volunteers worked in a residential centre for people with disabilities supporting those with palliative care needs. Volunteer activities varied according to the setting and a number of volunteers worked across more than one setting.

Three themes were identified which addressed the two questions asked of volunteers. These were framed as: 1) What volunteers do 2) How volunteers approach their work and 3) What working in HPC means to volunteers.

1. What volunteers do

The volunteer's contribution to HPC is mainly described as focusing on the patient and families' needs, with a smaller number also describing support to HPC organisations.

Patient and family support can take different forms and is described under two main sub themes: a) 'spending time with' and b) 'helping with practical tasks'.

a) Spending time with patients and families

Spending time with patients was a main category in all stories, regardless of whether the setting was a hospice, patients' homes, nursing home or hospital. 'Spending time with' is described as being with the patient, sensing what is going on and offering help. Volunteers describe sitting in silence, listening, reading aloud, or filling in crosswords.

"The best thing that we can do as volunteers is to simply be by another person's side. Sometimes, you don't need to say anything at all, you don't need to do anything extraordinary, it is simply your presence and a sincere desire to share another person's day to day problems that is the most beautiful gift that we can offer another person." [Poland, nr. 1]

An aspect of being with the patients was described as empathizing with emotions and suffering in the sense of being with a patient where the patient is emotionally at that time. This means offering presence with a compassionate attitude. This can take the form of not leaving the person alone, listening to what the patient experiences, or having conversations about topics of interest to the patient. Sometimes it means offering a shoulder to cry on or a voice to sing with. Some volunteers also report praying together with patients if asked, being there to share fears, and offering whatever the other needs or values in the situation.

“I can take their hand, sit in silence, breathe in the same rhythm. I can stroke their face, their forehead, speak softly, read a few sentences, recite a poem, sing a lullaby. Even if the person does not seem very aware, I often notice signs of relaxation - breath that calms down. I am alongside the life that is there. My presence often leads people to wonder about the meaning of their lives, which we then explore together.” [France, nr. 2]

After the death of the patient, some volunteers describe helping the family in different ways. These include helping to reorganise the house, helping families to find meaning and come to terms with loss and supporting family members at this time by talking, listening, sharing their pain or providing information.

“I find this work so interesting and rewarding. The key is to listen and let them know they are heard and understood. The grieving client is perhaps at their most vulnerable time of their life, suffering pits of despair. In the session, there is time for them to release their fears, offload their darkest secrets and even hidden issues from the past. Their cocktail of emotions. I feel honoured they have gained trust in me and can confide. It is soul searching for them and it is rewarding to see a client grow in acceptance and gain some hope.”[UK, nr. 2]

b) Helping with practical tasks

The second sub-theme was ‘helping with practical tasks’. This included helping with meals, taking patients to medical appointments, observing patients’ condition, shopping, helping with basic care, and changing bed linen. Volunteers also like making tea or meals for families, helping patients and families feel comfortable and at home. In patients’ homes volunteers sit with patients so family members can sleep, wash dishes, do laundry, shopping or provide information. If patients are in a care institution volunteers may welcome them at a reception desk. They take patients to mass or communion, or may prepare for celebrations in the hospice chapel.

Although not described by all participants, volunteers in a number of countries also described providing practical support to HPC organisations by organising fundraising events, placing charity collecting boxes, raising awareness, or help with promotional

activities. They also help with recruitment and training of new volunteers, or serve on boards of palliative care organisations.

2. How volunteers approach their work

What appeared striking when reading the stories, were the volunteers' descriptions of the manner in which they approached their activities and the way in which they are present in the lives of patients and families. The accounts provide clear insight into a way of being there that is similar throughout the European countries sampled, becoming visible in volunteers' presence, attitudes, intentions and the type of relational impact they aim for.

Volunteers described being there for patients in an attentive and open-minded way. Their attention is focused on understanding how patients picture their end-of-life journey, identifying wishes and what would help. They describe being respectful as a core value. They strive for shared humanity, being friendly and welcoming. Their focus is as open-minded as possible, by being attuned to the pace and uniqueness of every patient.

They describe being sensitive to expressions and gestures and to listening without interrupting. They make sure that they do not offer opinions or advice. Where possible they show that they are there to listen and understand, not focussing on tasks but being attentive to the responses of the patient. They create space for the other to share what is worrying them.

“Every one of us is unique and should be treated as such. To put oneself into another person's position is hard. I have learnt to be keen and to listen without interrupting or offering my own opinion or advice. We humans are all so alike and yet so different. Nowadays I feel that I better understand people from different backgrounds than mine. I feel that I have become more tolerant both towards myself and people I meet. It has become easier to let people live their own lives and to forgive”. [Finland, nr. 5]

Volunteers' stories show that they try to add to the quality of care at the end of life in a quiet and calm way. They describe offering wordless closeness by being there in a compassionate way and not seeking anything. Some volunteers describe this as being there 'naked of themselves' and trying to add to the situation via the 'power of silence'. The word love is often used in their stories as demonstrated in this quote:

“Paolo, Enrico, Martina, Sofia*, are a few patients that I remember with love: their thoughts or actions as a laugh, a cup of coffee, a song have made me better and they have taught me a deep sense of humility.” [Italy, nr. 5]

(*names changed)

In many stories the word 'heart' is mentioned. Volunteers write that they work from their heart, that they offer selfless love to another person as an answer to sorrow, pain and problems. They aim for small gestures and try to make everyone comfortable. They describe trying to soothe patients' feelings of fear and

restlessness when necessary. They also try to relieve loneliness, despair, helplessness and frustration. Not all interactions are intense however, volunteers also speak of laughter.

“Listening is most important and fortunately there is also humour. I would like to give an example. We helped a gentleman off the toilet. He had defecated. ‘This has been a long time ago’, he said. ‘Well, then it has to be a big relief’, we said. ‘No, that’s not what I mean’, he said. ‘That I’ve been that close to the breasts of a woman.’ ‘And what kind of breasts’, we said laughing.” (Netherlands, nr. 3)

Volunteers describe volunteering as more than offering practical help; it is about building relationships.

3. What working in HPC means to volunteers

The majority of volunteers found significant meaning in their work. Volunteering was not considered to be a casual activity, but an important, valued and meaningful part of their lives. They described both the rewards and difficulties of volunteering with people with palliative and end of life care needs. Whilst these were not present in all narratives, three recurring themes emerged from the majority of stories: a) giving extra meaning to their own life and bringing new perspectives b) experiencing emotions and impact, and c) personal development and achievement.

a) Giving extra meaning to own life and bringing new perspectives

Volunteers shared how working in this field gave meaning to their own lives. They described learning much from being with patients as they dealt with their approaching end of life. Volunteers came to understand more about life and death, appreciating life and spoke of learning from sorrow. Patients were described by some as teachers.

“I have been a volunteer at X hospice for five years. In general I remember everyone I met in these years. Everyone taught me something, [Italy, nr. 2]

Volunteering gave people opportunities to spend their time in meaningful ways. Some felt their life had been enriched by working with patients and described experiencing meaningful and peaceful moments, with each encounter with patients described as an ‘adventure’. Volunteering in HPC brought more than some participants expected, helping them to feel needed, facilitating the development of friendships and giving great satisfaction. Others gained a sense of inner peace, helping them to stay grounded by realising what was important in life. Another described becoming “a richer, grateful person.”

Reflecting upon how different patients responded to their approaching death also brought meaning. Volunteers described their experiences as broadening horizons and giving new perspectives on life. One volunteer wrote of learning new ways to look at sickness, sorrow, loss and to accept the impending death of those she supported. Another described how they came to understand the complexity of death:

“I experienced that this work (in the home and also in the hospice) has had a purifying influence on me... I experience dying as an “active deed” and as a large mystery, that redeems man from his suffering. I would wish for every human, that he/she can end his life at home in a manner worthy of a human being.” [Netherlands, nr. 5]

Volunteering also offers an opportunity to be part of a community of volunteers, ‘people with wonderful hearts’.

b) Experiencing emotions and impact

Volunteers also wrote of satisfaction, fulfilment and joy in helping others. Volunteering was experienced by one person as making him stronger and of being fulfilled by understanding more about the dying person, their family and professional caregivers. He experienced each death as unique, making the volunteer face his own mortality. He felt gratitude in being capable of and permitted to undertake this work. Others spoke of volunteering helping them to understand the true meaning of life. One volunteer perceived this to be about “love for their fellow human being”, enhancing their joy in nature, valuing the here and now and making material things less important. Another described their experience as “making me become more human, in love, in caring, in attention, but also thankful for everything around me”. Others wrote of experiencing positivity, care and love and the importance of embracing diversity, tolerance, respect.

“I discovered a great joy in helping others, even though sometimes this role is difficult... However, the joy experienced by sick patients when they realise that they are not alone and that someone is thinking of them, is priceless.” [Poland, nr. 3]

There was also much meaning for volunteers in the emotional impact arising from the varied and contrasting emotions that this work evoked. Some described the challenges of work that can be emotionally difficult at many levels engaging “the heart, the emotions and the body”. One volunteer described the variety of engagement with patients from the light-hearted in trying to bring patients “a moment of joy” to the “intense and serious conversations” about death and dying. Some found that the age of the patient made their experience more challenging, such as caring for young people and people of the same age who were dying.

"It is true, of course, that the encounters with the people coming to the day hospice leave painful marks on my soul. Nevertheless, engaging with these people broadens my horizons and gives me new perspectives for my own life that shape my personality" [Austria, nr. 2].

c) Personal development and achievement

Volunteering was described as an important part of life, giving opportunities for learning, personal development and gaining experience in care. One volunteer described the experience as helping "to break down my barriers and weaknesses", "shaped my character and personality and helped me to build relationships with people who I meet outside of the hospice in my everyday life." Others described gaining new friends and networks through volunteering, viewing volunteering as a two-way: "gift" to patients and "community of volunteers".

"To be a volunteer means a lot to me. I have the opportunity to meet people with common interests: keeping in contact with others protects me against stress and anxiety. To be a volunteer gives me a sense of pride and identity". [Italy, nr. 4]

Volunteers believed that they had become more confident, stronger, tolerant and forgiving as a result of their experience. Others had achieved significant goals at the same time as learning to face their own fears about illness and death. Volunteers felt privileged that patients allowed them to be alongside them at the end of life and of being "thankful, because ... I am allowed to be there."

Some volunteers expressed pride in their achievements, gaining satisfaction from knowing that their contribution could "lighten the burden" for patients and families.

"It felt good for me to see that I could bring some peace in the sometimes tense, emotional or even hectic situation." [Netherlands, nr. 1]

Another volunteer described their work as "some of the best and most positive experiences of my life". In contrast, one volunteer did not see much meaning in volunteering, viewed death as natural and had no fear of death.

"The time spent with the dying has not made me think about my own death. I also do not think that my experience in end of life care would help me face my own death in the least." [Finland, nr. 3]

Discussion

This paper provides an analysis of volunteers' accounts from eight European countries. The narratives from different countries show great similarity in activities: spending time with patients and family members, performing practical tasks with patients and providing organisational support. The analyses identified three recurring themes with respect to experience and meaning making. Volunteering brings extra meaning to life, brings new perspectives and provides fulfilment and joy as well as a sense of being part of a community.. Volunteers experience personal development resulting from their work. This confirms findings from previous studies in terms of types of activities, experienced challenges and reported impact on volunteers' lives (10,11,13,14).

Some current research on HPC volunteering (6,7), frames volunteering by roles or activities, By framing volunteering from this external perspective the essence of what it means to work as a volunteer might be missed. Comparing the richness of the narratives analysed and characteristics of the themes found, we identify a potential gap between research that mainly maps the role and activities of volunteers in HPC, and the narratives analysed in this study. Earlier studies describe performing practical tasks, providing social, emotional and spiritual support (4,8). Use of these words risk volunteers being perceived as 'helpers' of care professionals, solely adding to the domain of social, psychological or spiritual caregiving as lay people. This frame consists of language that refers to symptoms, needs, and 'interventions' that add to maintaining or improving quality of life.

In order explore this further three conceptual tensions will be discussed: 1) a within perspective of volunteer expertise, 2) a perspective of volunteers in the team and 3) a perspective of impact. The first tension relates to understanding of what volunteers 'bring' as expertise. In this study, the wording used by volunteers in their accounts illustrate cognitive frameworks in action that focus on attunement, building relationships and becoming who or what the other needs. These cognitive frames relate to sharing experiences, being with, sharing emotions, sharing vulnerabilities, offering (unconditional) love. This suggests, therefore, that trust, space and reflection on boundaries and moral dilemmas are helpful attributes to contribute to the success of HPC volunteering. Whilst HPC volunteers are sometimes considered to be helpers of professionals, this perception of volunteering potentially undervalues their contribution. The expressed aim of volunteers to become the spark that is able to light up another person's life might be helped by a frame that distinguishes qualities of opening up to the others' experience, quality of compassion manifested and 'reading' concerns experienced at the end of life (20). Concepts of presence and presencing might help to further clarify this type of relational expertise as well as ways to improve and evaluate the 'being with' role and experience of volunteers (21).

The second tension addresses the concept of liminal space in volunteering practices. Vanderstichelen, et al. (9) described the value of volunteers as meaningful in a discrete space between professional and family caregivers and the dying person.

They occupy a liminal space – a location where one is neither in the previous nor in the following stage or place but rather in a fluid, malleable place that enables new practices to emerge. Their contribution can be mapped then as a liaison function between professionals, family members and patients in which reciprocity of humanity between patients and volunteers can exist. A space where a person's transition towards death is supported (22).

Understood in this way, volunteers sometimes fulfil an advocacy role in which they communicate concerns or missed signals of patients and families to care professionals. This important contribution enables liaison between family members, patients and paid staff in a space that discrepancies are observed. Sometimes volunteers can fill identified care gaps themselves, and sometimes they enable and support care professionals or family members to adapt better to the needs of the dying person.

Therefore, the third tension indicated that the impact of volunteering can be hindered or facilitated by the framing of the volunteering contribution. It is possible that focussing on the type of mapping to frame HPC volunteering contributes to the reduction of the impact of volunteering. What might be missed is their impact on reduction of existential loneliness, on helping people to come to terms with life issues enabling them to feel heard, seen and acknowledged as a unique human being, rather than as a patient.

This latter framing addresses a human quality that could be offered by every member in a community to every other member in a community. Highlighting this aspect of volunteers' contribution to the inclusion of dying people and their family members in communities, also demonstrates the function of volunteers as role models to other community members who might be uncertain about maintaining contact with patients and families approaching death.

Strengths and Limitations

The strength of this project comes from the willingness and openness of volunteers to share their very personal experiences of HPC volunteering. They appear to have thought deeply about their work and were prepared to share their challenges and vulnerabilities. One of the limitations is the small number of volunteers stories from each country and so the findings, although similar across countries, are not necessarily transferable to that country or throughout Europe. The literature review included papers written only in English thus limiting background data. The stories were also translated into English from the language in which they were written. Although this was done carefully to preserve meaning, it must be recognised that the quotes come from translated text. The volunteers were identified by country contacts and it is possible that there may some inherent bias in terms of the volunteers who were selected.

Conclusion

Volunteering is far from a casual activity as it involves sensitivity, much reflection and consideration of all that volunteers experience in their role. To volunteers it is not about tasks, but about a part of their life, the impact upon which can be significant. The results of this paper therefore add to the understanding of volunteers, in the sense of giving attention, being with, and offering compassion as a community resource to patients and families in difficult situations. Theories about presence and presencing might have value in further underpinning this contribution to palliative care. Understanding the extent and depth of the volunteers' experience will help to prevent the reduction of their contribution and increase the impact of their involvement. Therefore, educating care professionals, managers and policy makers about the rich, relational images described by volunteers and cognitive framing of volunteers and their impact, might be helpful in improving contexts that strive to enable the flourishing of HPC volunteering. It would be of value to extend this type of research and explore more widely in other countries.

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